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ABSTRACT

Input from a variety of viewpoints is essential in complex policy discussions. Families serving on local interagency coordinating councils (LICCs) and state interagency coordinating councils (SICCs) should reflect the diversity of families served within the early intervention or preschool service system with respect to income level, ethnicity, gender, age and diagnosis of child. There are a variety of ways in which parents can get involved, from volunteering, to receiving reimbursement for their work, to being hired as part or full time consultants. More and more states are developing realistic reimbursement policies and simple procedures for requesting cost reimbursement in order to help create a level playing field for all families. A number of state programs are also hiring parents as liaisons or consultants to help weave the family perspective into the work of the agency. This involves specific challenges such as training and support for the parent/consultant, ensuring job security, and helping parents adapt to their new roles. There are a growing number of parents with experience in all of these roles to seek out for advice and support. This article reflects discussions about these issues at ICC parent meetings and conference calls coordinated by NECTAS (National Early Childhood Technical Assistance System) in 1995 and 1996. (SG)

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EARLY CHILDHOOD BULLETIN

ENHANCING FAMILY ROLES IN EI PROGRAMS

By

BARBARA K. POPPER

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EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils
Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC*TAS

November 1997

Enhancing Family Roles in EI Programs

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Over the years, states have addressed the problem of how to involve a diversity of parents in the activities of their state interagency coordinating councils (ICCs). One strategy has been to provide reimbursement to parents for expenses they incur when participating in meetings and activities related to serving on a state or local ICC. In 1990, a few states were beginning to pay parents' expenses for serving as members of their councils. While these were not salaries, they did represent recognition that parents should not be burdened by the extra costs of their volunteer work because that would limit the ability of interested parents to participate. A report on this practice, "State Support for Parents on Interagency Coordinating Councils," by Martha Gentili, appeared in an issue of the NEC*TAS *Early Childhood Bulletin* (Spring/Summer 1990). Ms. Gentili cited the background for funding parents along with examples and a rationale for paying parents for their time in addition to covering their out of pocket costs. In the past seven years, more states have established policies to do so. This article reflects discussions held at the ICC parent meetings of NEC*TAS meetings in 1995 and 1996 and on subsequent conference calls. It will focus on issues to consider with possible solutions.

Financial support for council work

As parent involvement at the program and policy level for their children becomes more accepted and appreciated, parents have begun to talk about ways in which they are supported in their participation. At NEC*TAS meetings and other informal meetings, parents discuss the difficulties they often face when trying to balance their volunteer commitment with the reality of their lives, including job responsibilities, travel costs and child care expenses. While it is flattering to be invited to participate on task forces and committees such as local and state Interagency Coordinating Councils (ICCs), there are other considerations that confront families. Many employers are now more willing to allow parents to take time off for involvement in their children's schools and early intervention programs. In the spirit of volunteerism, parents can request of employers that they permit them time off to serve as members of committees for their children's programs to help ensure effective services for all children.

Whether parents are using their own time or donated work time, they may incur expenses that would be out of pocket costs of participation. Parking in a downtown area can cost $10-15 for only a few hours. A long drive to a meeting site can mean gas, toll charges and a meal need to be covered. Babysitter charges can bring the cost of the meeting up high enough for parents to think about their family's budget. Asking about reimbursement for expenses, and even for a salary or consultant fee, if not on their employer's time, for time spent at meetings, can be an uncomfortable conversation, especially when parents themselves feel that these activities are volunteer work. Several parents have articulated that while they willingly contribute their time and energy to their tasks, they are not always in a position to absorb the costs of participation. Even when parents begin to think about requesting funds, they aren't always clear about whom to ask. They may

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also worry that if they do bring up the issue, the invitation to participate might be withdrawn and offered to someone who might not request reimbursement. When expenses are covered for all parents who participate, parent leaders can freely offer to become involved and invite other parents to do so without having to worry about the ability of those parents to pay for expenses. Professionals can also feel free to invite all parents to consider participation with costs reimbursed.

Input from a variety of viewpoints is essential in complex policy discussions. The families serving on LICC or SICC committees should reflect the diversity of families served within the early intervention or preschool service system with respect to income level, ethnicity, gender and age of parents, and diagnosis of child. Realistic reimbursement policies and simple procedures for requesting cost reimbursement help create a level playing field for all families. "Strategies for Recruiting Family Members from Diverse Backgrounds for Roles in Policy and Program Development," by Kim Brame, appeared in *Early Childhood Bulletin* (Summer 1995) and includes very specific suggestions for inviting a wider group of parents to participate.

More and more states are setting policies that will help parents attend meetings and be actively involved in trainings, workshops, and conferences. Costs of gas, tolls, parking, child care, and meals are well recognized as new policies are put into place. Policies vary from state to state, reflecting the particular needs of the region or state. For instance, in Alaska, air fare and hotel costs are covered because parents must travel great distances to meetings. In another state, arrangements are made to cover specialized child care, including nursing care. Often, stipends are offered to cover the cost of child care instead of reimbursement for actual cost. Several states reported that stipends were simpler than paying for actual costs since some children are left with family members who do not charge while others are in day care or nursing care.

Information from parents indicates that there is a wide range in the amount of reimbursement given. Stipends may range from $25/meeting to $150/meeting. These may be in addition to travel and child care costs to show recognition that the time parents spend is valued. Usually stipends are available for formal council meetings and committee meetings, but may not be available for training and conference opportunities. There is no way of knowing whether parents are discouraged from participating if the stipend rates are too low or not available. Currently, the amount of money involved is not enough of an incentive for participation by persons who would not otherwise choose to be involved.

In addition to setting policies about the amount of reimbursement, states must also consider how to provide reimbursement in a timely manner. State governments are seldom able to pay parents quickly and almost never able to advance money to cover expenses incurred that day. Michigan and many other states have used an existing nonprofit agency which promised to pay the parents within the week. New York exempts the reimbursement from being counted as family income so it will not jeopardize the family's eligibility for services. The complexities of parent reimbursement are further discussed in a recent publication by Elizabeth Jeppson and Josie Thomas, *Words of Advice*, from the Institute for Family Centered Care in Bethesda (1997).

Some parents have raised the question of accountability for their involvement. They want to know in advance if they are expected to report back to other parents or file a written report about their meetings. When might one parent be replaced by another who is interested in being supported to attend a conference or statewide meeting? Parents hope that policies will encourage involvement of more parents so that the load can be shared broadly instead of only one or two parents being asked repeatedly to participate or to be speakers. An issue of *Early Childhood Bulletin* (Spring/Summer 1994) addressed this aspect of parent involvement in the article, "Who You Gonna Call?" by Barbara Popper.

Employment as parent staff member

Another facet of the discussion relates to parents who begin to move from the volunteer level with or without limited stipends for their time to one of being paid a salary as a parent consultant or parent advisor for either part- or full-time work. State programs with a focus on children's health are beginning to hire parents as liaisons or consultants to help weave a family perspective into the work of the agency. The person hired may be expected to participate in all facets of work done by the program to assure a parent viewpoint or the employed parent may provide outreach to other parents and develop a parent network. A few other programs hire parents for jobs which do not specify parental expertise, but are often the first contact a parent has with a service program. Clerical staff or van drivers are frequently the first telephone or direct contact for a new family and having someone with the experience of having a child with special needs in that position can be extremely supportive for new families.

A survey of parents employed by Title V Maternal and Child Health funded state programs conducted in 1992 with a follow up in 1994 by the CAPP National Parent Resource Center project indicated that 22 states have already hired parents in part-time positions. For instance, Massachusetts has hired seven parents for their Part H program to provide parent leadership and five regional parents in their statewide Children with Special Health Care Needs (CSHCN) division to provide resource and referral regionally. These parents work as part-time employees, but meet together monthly to exchange information about program changes, upcoming events, ongoing training needs, and their own work experiences. Other states began hiring parents in the mid 1980s. Usually these were parents who had been serving as volunteers on committees and were known to the health departments. Other states advertised the positions and attracted parents not previously known to their professional staff, but often linked to some parent organizations. In most cases these early parent consultants were pioneers and developed their own job description modifying it as their jobs developed.

Once a parent is hired as a consultant, three specific challenges are funding and job security, training and support for the consultant, and adapting to the change in roles once employed. Several parents have been funded by particular grants that then ran out leaving the parent searching for new grants or other support. In some cases the state incorporated the parent position into other ongoing funding as a budget line item. Other parents have found that as states reorganize and downsize, their jobs were cut along with others. There is little job security relying on either grant money or line item jobs these days. Parents interviewed for the CAPP report described a variety of orientation and ongoing training and support available to them. Often a department person served as mentor and a source of support. Other parents received no formal training or orientation. In addition, because the parent is employed because of their parenting and volunteer experience in the system and not necessarily for their previous education or job experiences, evaluation of their work has been a challenge for both the parent consultant and the supervisor. Because the job description is frequently new and evolving, some mentorship from a supportive supervisor is essential. As parents move from a position of volunteer or family advocate to that of paid employment, other issues need to be considered. Is there any involvement the parent would have to give up to be part of the program? Being the officer of a parent advocacy organization would not be a good idea when working for the state. Other officers could continue to speak freely for the organization, but the parent employed by the program would have to give up the leadership role in the organization. Parents would also need information about other limitations that might be placed on state workers.

There are other considerations to being part of an official state program. The employed parent

may feel separated from other parents. Keeping in touch with a constituency is essential. Some of the constituents might keep their distance while others expect more than the usual amount of support since the parent consultant is paid to be available. There are parallels in relationships to the professionals employed by state agencies. Some will accept the parent consultant as a fellow worker, and inspiration, while others might consider the parent an outsider without real credentials. All these reactions were among those reported in the CAPP survey of parents employed by state health departments and the state officials supervising them.

Conclusion

The amount of interest in this topic continues to be impressive. Evidence includes the CAPP report, the publications *Essential Allies: Families as Advisors* and the follow-up *Words of Advice* from the Institute for Family-Centered Care, as well as meetings of parents at NEC*TAS and the recent meeting of employed parents at the Association of Maternal and Child Health (AMCHP) Programs annual conference. Families now have growing evidence and experience to help them determine the range of roles they can play from volunteer with support from their employer for time spent; volunteer receiving a stipend or consultant fee; or staff member of the program as a paid part- or full-time parent consultant. There are now many parents with experience to seek out for advice and support. At some point, a new association devoted to the needs of employed parents may be created so that parents across the country, even one serving as a program's lone parent consultant, would have a peer group with whom to share experiences.

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*For additional information regarding specific guidelines for each state, refer to State ICC Overview, NEC*TAS, 1997, edited by Jo Shackleford*

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